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A cross-sectional study during COVID-19 of the social care-related quality of life of people with dementia and their carers in England

Measuring the outcomes of people with dementia who are unable to self-report and their carers (MOPED)

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Background

- Over 767,000 people living with dementia in England and Wales
 - The majority (~two thirds) live in their own home.
- Community-based social care is designed to maintain independence and QoL of people living with dementia and their unpaid carers.
- However, they are often overlooked in social care research.
 - E.g., Adult Social Care Survey in England (ASCS) – exclusion of people unlikely to be able to self-report from sample.

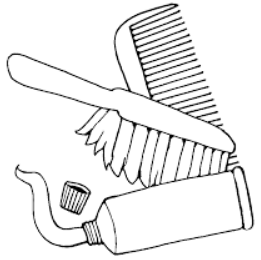
Aims

1. To establish the feasibility, construct validity and reliability of **ASCOT-Proxy**
 - Designed for use when someone is unable to self-report, even with adapted methods (e.g. adapted interview, easy read)
2. To establish the feasibility, construct validity and reliability of **ASCOT-Carer**
 - Previously validated in a heterogeneous sample of adult carers in England (Rand et al, 2015) and identified as a suitable instrument *by carers of people with dementia* (Gridley et al, 2019)
3. To determine the factors associated with the social care-related quality of life of people with dementia (**ASCOT-Proxy**, proxy-reported) and their carers (**ASCOT-Carer**, self-reported)

Methods

- A survey of carers of people living with dementia in England
- Online or postal questionnaire
 - Individual characteristics
 - **Carer:** age, gender, ethnicity, overall health
 - **Care-recipient:** age, overall health, I/ADLs, cognitive status
 - Caregiving situation: hours of care per week, co-residence, and self-reported financial impact of caring
 - Type, intensity and satisfaction with community-based care services
 - Outcome measures
 - **Self-report:** ASCOT-Carer, EQ-5D, C-DEMQOL, CES
 - **Proxy-report:** ASCOT-Proxy, EQ-5D-Proxy, DEMQOL-Proxy

ASCOT-Proxy



Personal cleanliness
and comfort



Food and drink



Personal safety



Clean and comfortable
home



Social participation
and involvement



Control over daily life



Occupation

*Doing things that I
value and enjoy*



Dignity

23. Thinking about the food and drink the person you represent gets, which of the following statements best describes his/her situation?

Please say what you think in the first column. Then say how you think the person you are representing would answer in the second column. Please write in the comments box if you wish to add anything to your answer.

The person I am representing...

Please tick (✓) one box for each column

	My opinion (What I think)	What I think the person I represent thinks
Gets all the food and drink s/he likes when s/he wants	<input type="checkbox"/>	<input type="checkbox"/>
Gets adequate food and drink at OK times	<input type="checkbox"/>	<input type="checkbox"/>
Doesn't always get adequate or timely food and drink	<input type="checkbox"/>	<input type="checkbox"/>
Doesn't always get adequate or timely food and drink, and there is a risk to his/her health	<input type="checkbox"/>	<input type="checkbox"/>

- Ideal state
- No needs
- Some needs
- High-level needs

ASCOT-Carer



Social participation
and involvement



Control over daily life



Occupation

*Doing things that I
value and enjoy*



Personal safety



Feeling supported
and encouraged



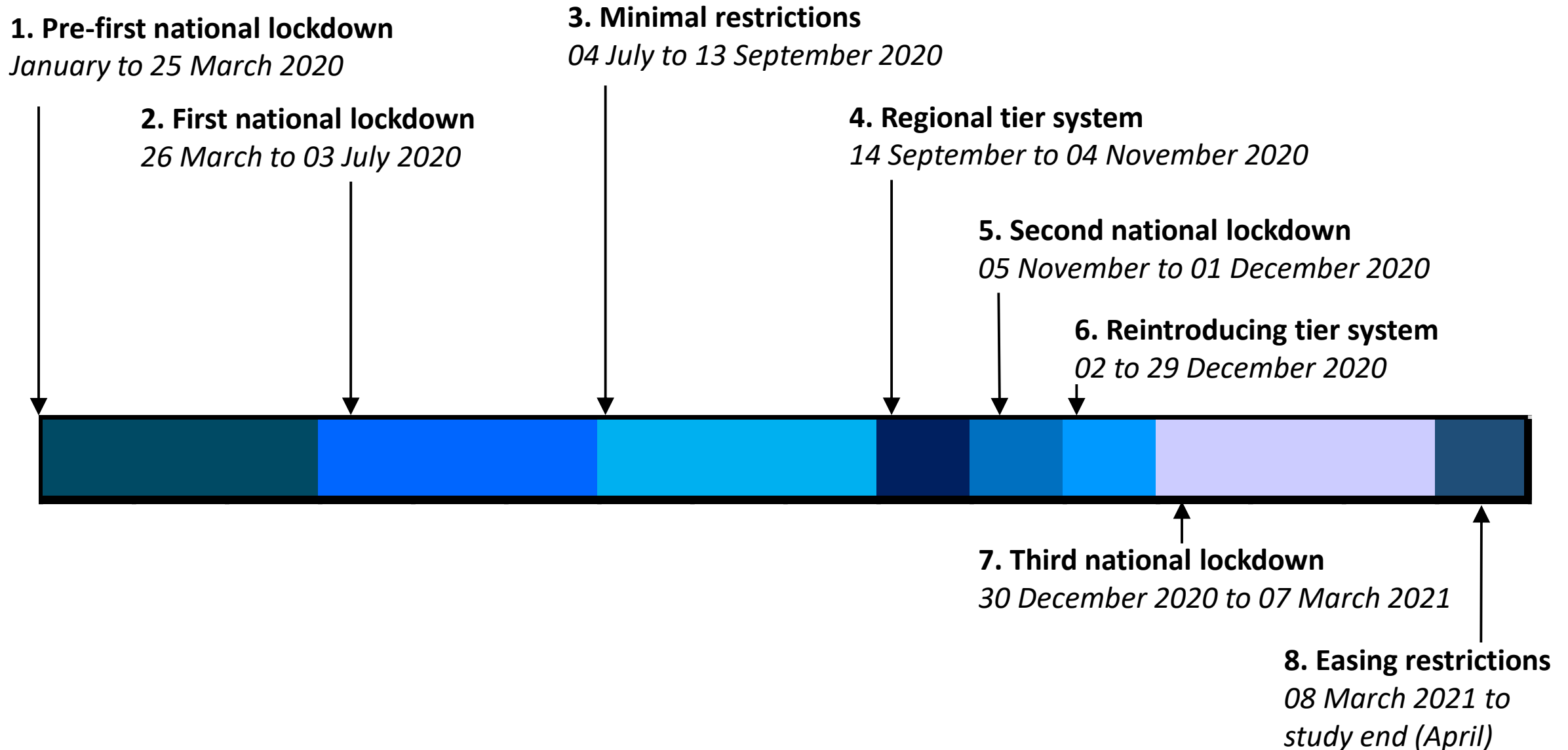
Self-care

*Eating well, exercise,
sleep, medical
appointments*



Time and space
to be myself

COVID-related Policy Phases in England



Participants

Inclusion criteria:

A friend or family member of someone living with dementia, who:

- Lives at home (not in a nursing or residential care home)
- Uses at least one type of social care service
- Would not be able to answer a postal or online questionnaire, even with help.

Carers:

- Average age of 62.4 years
- 75.7% female
- 94.6 % white/white British
- 47% provided ≥ 50 hrs of care per week

People with dementia:

- Average age of 81.5 years
- 48.9% were parents of carer
- 41.5% were partners/spouses of carer
- 57.8% lived in same household as carer

Unmet Social Care Need (% of sample, $n=313$)

	ASCOT-Carer	ASCOT-Proxy <i>proxy proxy</i>	ASCOT-Proxy <i>proxy person</i>
Home cleanliness and comfort		10.9%	4.5%
Personal cleanliness and comfort		14.4%	4.5%
Food and drink		15.7%	10.2%
Dignity		21.1%	35.1%
Control over daily life	51.8%	55.3%	52.7%
Occupation	71.6%	74.8%	60.1%
Social participation	58.8%	62.9%	49.5%
Personal safety	3.2%	11.8%	16.0%
Self-care	32.1%		
Time and space	62.6%		
Feeling supported and encouraged	50.2%		

Results: ASCOT-Carer

	B	95% CI	p value
Male	.039	-.005 to .083	.082
Aged ≥ 65 years	.019	-.025 to .063	.403
Ethnicity: Black, Asian, multiple/mixed	-.072	-.155 to .011	.088
Self-rated health: good or very good	.124***	.082 to .166	<.001
MDS CPS: severe impairment	-.057**	-.094 to -.019	.003
Co-resident with care-recipient	-.059*	-.117 to -.001	.044
≥ 50 hrs care per week	-.069*	-.124 to -.013	.015
Financial difficulty due to caring	-.094***	-.132 to -.056	<.001
Satisfied with services	.142***	.105 to .178	<.001
Survey completion by C-19 phase	-	-	Not Sig.
Survey online	-.021	-.073 to .032	.443
Constant	.651***	.562 to .739	<.001

* <.05, ; ** <.01 *** <.001

Results: ASCOT-Proxy

- **Proxy-Proxy rating**

- Suitability of home design; co-resident with carer; >50 hrs unpaid care/week; hours of home care per week; use of day services or activities (+ve)
- Severe cognitive impairment; regional tier system (Sept/Nov 2020) (-ve)

- **Proxy-person rating**

- Aged 65+; I/ADLs with difficulty; severe cognitive impairment; reintroducing tier system (Dec 2020); third national lockdown (Dec 2020 to March 2021); easing restrictions (March 2021 to study end) (-ve)
- Paid and unpaid care intensity or type (Not Sig.)

Conclusions

- High % of unmet social care-related need, especially among carers
- Those carers at risk of poor social care-related QoL are those with poor health, caring for ≥ 50 hrs/week, and experiencing financial difficulties due to caring
- Satisfaction with care associated with better outcomes for carers
 - 'Whole family approach'
 - 'Think carer'
- Impact of C-19 restrictions
 - No significant association with carers' QoL
 - Significant negative association with PLWDs' QoL
 - At introduction of restrictions with a tier system (**proxy proxy**)
 - At latter stages from reintroduction of tier system through to study end (**proxy person**)

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